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ABSTRACT

This report presents the Government Accounting Office's recommendations regarding standards for determining eligibility for Supplemental Security Income (SSI) based on a childhood disability. The report is based on the Social Security Administration's (SSA) monitoring of 288,000 children whose eligibility was subject to review and of 370,000 new applicants. Overall, the report finds that SSA has made considerable progress in implementing the welfare reform changes in eligibility for SSI children. However, because SSA's medical listings reflect multiple levels of severity, SSA needs to expedite the updating and modification of its medical listings to ensure that all children are assessed against a uniform severity standard. SSA also needs to take concerted action to follow through on its plan for monitoring and continually improving the quality of decisions regarding children. Other findings indicate that fewer children are affected by new welfare reform restrictions than was earlier estimated, and existing regulations generally set severity standards at two marked or one severe functional limitation. A response from the SSA notes the agency's need to consult with medical experts to ensure that listings reflect state-of-the art medical practice and that the listings revision process will take several years. (DB)

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United States General Accounting Office

GAO

Report to the Chairman, Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives

May 1998

SUPPLEMENTAL SECURITY INCOME

SSA Needs a Uniform Standard for Assessing Childhood Disability

ED 420 150

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Health, Education, and
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B-279558

May 6, 1998

The Honorable E. Clay Shaw
Chairman, Subcommittee on Human Resources
Committee on Ways and Means
House of Representatives

Dear Mr. Chairman:

In 1997, almost 900,000 children younger than 18 received about $5 billion in Supplemental Security Income (SSI) benefits. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193), commonly referred to as welfare reform, made eligibility for childhood SSI benefits more restrictive.[1] In February 1997, the Social Security Administration (SSA) published regulations to implement the new definition of disability for the SSI children's program set forth in the welfare reform law. Under the more restrictive standard, a child's impairment generally must result in marked limitations in two areas of functioning or an extreme limitation in one area. Previously, a child could be found eligible if his or her impairment resulted in one marked and one moderate limitation or three moderate limitations.

In September 1997, we reported that SSA's regulations establishing a new severity standard are consistent with the law and are well supported.[2] Since then, we have been monitoring SSA's adjudication of cases under the new regulations for 288,000 children whose eligibility was subject to review against the new standard as well as for about 370,000 new applicants. You asked us to expand on our early findings regarding SSA's implementation of the new eligibility standard, which we reported to you and the Chairman of the Social Security Subcommittee in a joint hearing on March 12, 1998.[3]

Results in Brief

SSA has made considerable progress in implementing the welfare reform changes in eligibility for SSI children. It has taken important steps to

[1]Sec. 232 of P.L. 104-193 mandates that we report to the Congress by January 1, 1999, on (1) the effect of the legislative changes on the SSI program and (2) the extra expenses incurred by families of children receiving SSI who are not covered by other public programs. This report is based on our work to date under the first mandated study.

[2]Supplemental Security Income: Review of SSA Regulations Governing Children's Eligibility for the Program (GAO/HEHS-97-220R, Sept. 16, 1997).

[3]SSA's Management Challenges: Strong Leadership Needed to Turn Plans Into Timely, Meaningful Action (GAO/T-HEHS-98-113, Mar. 12, 1998).

safeguard fairness by identifying children whose benefits may have been terminated inappropriately and establishing remedial action to rereview their cases. However, because SSA's medical listings reflect multiple levels of severity, SSA also needs to expedite updating and modifying its medical listings to ensure that all children are assessed against a uniform severity standard. The need to revise the listings is a long-standing problem that we reported 3 years ago. Moreover, SSA needs to take concerted action to follow through on its plan for monitoring and continually improving the quality of decisions regarding children. Consistent with our legislative mandate, we will continue to focus our work on SSA's efforts to provide reasonable assurance that it can administer the program consistently and improve the accuracy of childhood disability decisions.

Background

The Congress made the eligibility criteria for children to receive SSI more restrictive in order to help ensure that only needy children with severe disabilities are eligible for benefits. From the end of 1989 through 1996, the number of children younger than 18 receiving SSI had more than tripled, from 265,000 to 955,000. This growth occurred after SSA initiated outreach efforts and issued two sets of regulations that made the eligibility criteria for children less restrictive, particularly for children with mental impairments.[4]

One regulatory change, issued in December 1990, revised and expanded SSA's medical listings for childhood mental impairments by adding such impairments as attention deficit hyperactivity disorder and incorporating functional criteria into the listings. Examples of such functional criteria include standards for assessing a child's social skills; cognition and communication skills; and the ability to concentrate, keep pace, and persist at tasks at hand. The medical listings are regulations containing examples of medical conditions, including both physical and mental impairments, that are so severe that disability can be presumed for anyone who is not performing substantial gainful activity and who has an impairment that "meets" the criteria—medical signs and symptoms and laboratory findings—of the listing. Since the listings cannot include every possible impairment or combination of impairments a person can have, SSA's rules also provide that an impairment or combination of impairments can "equal" or be "equivalent to" the severity of a listing. There are separate listings for adults and children. The childhood listings are used first in evaluating childhood claims. If the child's impairment does not

[4]Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994).

meet or equal the severity of a childhood listing, the adult listings are considered.

The second regulatory change, issued in February 1991 in response to the Sullivan v. Zebley Supreme Court decision, added two new bases for finding children eligible for benefits, both of which required an assessment of a child's ability to function: functional equivalence, which was set at "listing level" severity, and an individualized functional assessment (IFA), which was set at a lower threshold of severity.

Functional equivalence is based on the principle that it is the functional limitations resulting from an impairment that make the child disabled, regardless of the particular medical cause. It was added as a basis for eligibility in response to the Supreme Court's determination in the Zebley case that SSA's medical listing of impairments—which had been the only basis for eligibility—was incomplete. Under functional equivalence, a child could be found eligible for benefits if the child's impairment limited his or her functional ability to the same degree as described in a listed impairment. Functional equivalence is particularly appropriate for assessing children with combinations of physical and mental impairments.

The IFA allowed children whose impairments were less severe than listing level to be found eligible if their impairments were severe enough to substantially limit their ability to act and behave in age-appropriate ways. A child was generally found eligible under the IFA if his or her impairment resulted in moderate functional limitations in three areas of functioning or a marked limitation in one area and a moderate limitation in another area.[5]

In 1995, we reported that the subjectivity of the IFA called into question SSA's ability to ensure reasonable consistency in administering the SSI program, particularly for children with behavioral and learning disorders. We suggested that the Congress consider eliminating the IFA and directing SSA to revise its medical listings.[6]

[5] Under the IFA, areas of functioning were assessed on the basis of children's ages. Social communication, cognition, and motor skills were assessed for children of all ages. Responsiveness to stimuli was assessed in children under age 1; personal and behavioral skills were assessed for children aged 1 and older; the ability to concentrate, persist at tasks at hand, and keep pace was assessed for children aged 3 and older.

[6] Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995.)

Welfare Reform Restricts Childhood Eligibility for SSI Benefits

Several welfare reform provisions enacted in August 1996 made the eligibility criteria for disabled children more restrictive: (1) childhood disability was redefined from an impairment comparable to one that would prevent an adult from working to an impairment that results in "marked and severe functional limitations," (2) the IFA was eliminated as a basis for determining eligibility for children, and (3) maladaptive behavior was removed from consideration when assessing a child's personal or behavioral functioning. Thus, such behavior would be considered only once—in the assessment of that child's social functioning—when determining whether the child had a mental impairment severe enough to meet or equal the medical listings. The law also required SSA to redetermine the eligibility of children on the rolls who might not meet the new eligibility criteria because they received benefits on the basis of the IFA or maladaptive behavior.

Fewer Children Are Affected by the Law Than Was Earlier Estimated

Earlier legislative proposals under consideration in 1995 might have removed from the rolls as few as 45,000 to as many as 190,000 children, according to Congressional Budget Office (CBO) estimates. After the welfare reform legislation was enacted in August 1996 but before SSA issued its regulations, CBO estimated that about 170,000 children on the rolls would no longer be eligible for benefits. After SSA issued its regulations in February 1997, CBO and SSA estimates of children who would be removed from the rolls were very close—131,000 and 135,000, respectively.

SSA identified 288,000 children as potentially affected by the changes in the eligibility criteria because they had been awarded benefits on the basis of the IFA or maladaptive behavior. Through January 31, 1998, SSA reviewed the eligibility of 271,489 of the 288,000 children. Of these, 137,090 (50.5 percent) were found eligible to continue to receive benefits and 134,399 (49.5 percent) were found ineligible. Because the number of children deemed ineligible does not yet reflect the results of all appeals, we do not yet know the final outcome on all these cases. Children initially deemed by a disability determination service to be ineligible have 60 days to request reconsideration of their case. If they continue to receive an unfavorable result, they can appeal to an SSA administrative law judge and, finally, to federal court. Recipients can elect to continue receiving benefit payments during the appeal process. Factoring in appeals and experience in conducting redeterminations so far, SSA now estimates that 100,000 children will be removed from the rolls as a result of the redeterminations.

SSA's Review Identified Implementation Problems and Initiated Corrective Actions

In December 1997, SSA issued a report on its "top-to-bottom" review of the implementation of the new regulations to address concerns that children may have had their benefits terminated unfairly.[7] SSA found problems with the adjudication of claims for which mental retardation was the primary impairment as well as potential procedural weaknesses relating to notification of appeal rights and termination of benefits for failure to cooperate with SSA requests for information needed to redetermine eligibility.

To remedy these problems, SSA intends to rereview all children whose benefits were terminated or denied on the basis of mental retardation. SSA conducted training in March 1998 to clarify how these claims should be adjudicated. Also, all cases terminated because families did not cooperate with SSA in processing the claim, such as by failing to provide requested medical information or to take the child for a consultative examination, will be rereviewed. SSA found that in two-thirds of these terminations, all the required contacts had not been made or had not been documented in the file. Finally, families of children whose benefits were terminated but did not appeal are being given an additional 60-day period in which to appeal their terminations. Notices of this right as well as the right to continue to receive benefits while the appeal is pending were sent out in February 1998.

Regulations Generally Set Severity at Two Marked or One Extreme Limitation

To implement the new law, SSA issued interim final regulations establishing a new severity standard in February 1997, which we found to be consistent with the law.[8] The regulations define an impairment that results in "marked and severe functional limitations" as one that meets or medically or functionally equals one of SSA's medical listings.[9] For a child to be determined eligible for benefits under this new and stricter standard of severity, the child's impairment must generally result in marked functional limitations in two areas of functioning or an extreme limitation in one

[7] For more information, see SSA, Social Security: Review of SSA's Implementation of the New SSI Childhood Disability Legislation (Baltimore, Md.: 1997).

[8] In light of the congressional mandate to issue regulations needed to carry out the new statutory provisions as expeditiously as possible, SSA determined that there was good cause to waive the notice of proposed rulemaking procedures. Instead, in accordance with the Administrative Procedure Act, SSA issued interim final regulations with a request for public comments. SSA stated that it would issue revised rules if necessary.

[9] Previously, the IFA afforded children whose impairments were not severe enough to meet or equal SSA's listings an additional basis on which to qualify for benefits. The IFA, which was set at a lower severity standard than the listings, was analogous to the test of residual functional capacity for adults whose impairments are not of listing level severity. Now, unlike adults, children can qualify only under the listings.

area. SSA also eliminated the IFA and removed the duplicate consideration of maladaptive behavior from the mental disorders listings.

In developing its regulations, SSA concluded that the Congress meant to establish a stricter standard of severity than "one marked, one moderate" limitation, for several reasons. The Congress eliminated the "comparable severity" standard of disability and the IFA, which was created for evaluating impairments less severe than those in the medical listings. A "one marked, one moderate" standard of severity would have retained one of the standards under which children were found eligible under the IFA, which SSA stated would violate the law. Finally, SSA interpreted the conference report to mean that the Congress intended the listings to be the last step in the disability determination process for children.

Some Children With Less Severe Disabilities Still Receive Benefits

Although SSA articulated the "two marked or one extreme" severity standard in its regulations, it did not modify its existing listings to specifically incorporate functional criteria that would reflect both the new definition of childhood disability and advances in medicine and science. For example, because of advances in treatment, some impairments no longer have as severe an effect on a child's ability to function as they once did. As a result, some listings are set below the "two marked or one extreme" threshold of severity, and cases are being adjudicated at this less severe level as well as at the "two marked or one extreme" severity level.

SSA has identified 28 listings that are most likely to enable children whose impairments result in fewer than two marked functional limitations or one extreme functional limitation to be awarded benefits. Our review shows that such less severe listings can serve as the basis for awards even though SSA rejected the "one marked, one moderate" level of severity in interpreting the "marked and severe" functional limitations required by the welfare reform law. Children who meet or medically equal these less severe listings qualify for benefits under the regulations. At the same time, SSA told us that the regulations prohibit the less severe listings from being used to determine functional equivalence. In March 1997, SSA stated that it planned to issue a Social Security ruling to clarify that only listings at the "two marked or one extreme" level were to be used in determining functional equivalence, but SSA has not yet issued such a ruling. In the absence of such clarification, some adjudicators may be using less severe listings in making functional equivalence determinations. Reviewers in SSA's Office of Program and Integrity Reviews have told us, however, that they would consider this an error.

SSA has not identified how many children may have been awarded benefits on the basis of these less severe listings. SSA told us that unreliable coding of the listings used to determine eligibility makes it difficult to quantify the extent of this problem. We do know, however, that some of the listings below the "two marked or one extreme" threshold are for prevalent impairments, including two of six listings for the most common impairment—mental retardation—and three listings for cerebral palsy, one for epilepsy, and one for asthma. Other listings below the "two marked or one extreme" threshold include one listing for juvenile rheumatoid arthritis, one for juvenile diabetes, and two for diabetes insipidus. SSA has not established a schedule for updating and modifying its listings.

SSA Is Taking Steps to Improve the Quality of Decisions on Children

SSA's quality assurance statistics on childhood cases show uneven accuracy rates across the states. Although nationally the accuracy rate for decisions on new childhood cases and redeterminations exceeds SSA's standard of 90.6 percent, many states fall below the standard. Specifically, for decisions made on new childhood cases from June 1997 through January 1998, 4 states fell below the 90.6-percent accuracy standard for awards, and 10 states fell below the standard for denials. For redeterminations, 10 states fell below the standard for continuances, and 10 states fell below the standard for cessations. Most of the errors have been in the documentation; that is, there was some deficiency in the evidence that formed the basis for the determination. In these cases, proper documentation of the case could substantiate or reverse the decision.

Given the significant changes in adjudicating cases on the basis of the new regulations, these statistics are not surprising. Moreover, childhood cases historically have been among the more difficult cases to adjudicate. We would expect SSA to be monitoring the decisions; identifying areas of difficulty for adjudicators; and providing additional clarification, guidance, and training to improve the accuracy of decisions. In fact, this is exactly what SSA has been doing, although its training schedule was delayed slightly.

Further, on February 18, 1998, SSA issued a memorandum detailing a new quality review plan for childhood disability cases to ensure correct and consistent application of the new regulations. The plan includes special initiatives to ensure the quality of cases readjudicated in response to the top-to-bottom review, as well as initiatives to improve SSA's ongoing quality assurance reviews on childhood cases. For the first time, SSA will be

drawing separate samples of new childhood claims and continuing disability reviews. This should allow SSA to provide more timely feedback and policy clarifications on the problems unique to adjudication of childhood claims. SSA also will be measuring the performance of its quality reviewers to ensure that they are accurately and consistently identifying errors. Under this effort, SSA plans to increase its sample of reviewed cases from 1,600 to 6,000 annually.

Conclusions

SSA has made substantial progress in implementing the new childhood definition of disability through its rapid redetermination of most of these cases, its action to ensure that the redetermination process is fair, and its ongoing review of the implementation of the new regulations. However, we remain concerned about how accurately and consistently the disability determination process is working for children. Specifically, because some of SSA's listings of impairments require less than "two marked or one extreme" limitation to qualify for benefits, SSA adjudicators are not assessing all children against a uniform severity standard. This is because SSA has neither updated its listings to reflect advances in medicine and science nor modified them to reflect a single standard of severity, despite its authority to do so. Moreover, we noted the need to revise the listings 3 years ago. SSA also needs to continue its efforts to improve decisionmaking for childhood cases to better ensure that adjudicators apply the new eligibility criteria accurately and consistently.

Recommendation to the Commissioner of Social Security

In view of the fact that many of SSA's medical listings for children are outdated and allow eligibility to be based upon multiple standards of severity, we recommend that the Commissioner act immediately to update and modify its medical listings to incorporate advances in medicine and science and to reflect a uniform standard of severity.

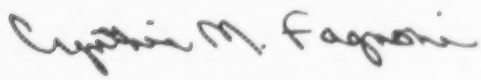
Agency Comments

We provided a draft of this letter to SSA for review and comment. SSA officials agreed that SSA should periodically update its listings and stated that it is developing a schedule to accomplish this. The agency stated that it must consult with medical experts to ensure that the listings reflect state-of-the-art medical practice and estimates that it will take several years to complete the revision. However, the agency did not address the need for the listings to reflect a uniform severity standard.

SSA also made some technical comments, which we incorporated where appropriate.

We are providing copies of this report to the Commissioner of Social Security and other congressional committees with an interest in this matter. We will also make copies available to others upon request. Please contact me on (202) 512-7215 if you have any questions about this report. Other major contributors are Cynthia Bascetta, Ellen Habenicht, Carol Petersen, and Daniel Schwimer.

Sincerely yours,



Cynthia M. Fagnoni
Director, Income Security Issues

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Children Receiving SSI by State (GAO/HEHS-96-144R, May 15, 1996).

SSA Initiatives to Identify Coaching (GAO/HEHS-96-96R, Mar. 5, 1996).

Supplemental Security Income: Growth and Changes in Recipient Population Call for Reexamining Program (GAO/HEHS-95-137, July 7, 1995).

Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995).

Social Security: Federal Disability Programs Face Major Issues (GAO/T-HEHS-95-97, Mar. 2, 1995).

Supplemental Security Income: Recent Growth in the Rolls Raises Fundamental Program Concerns (GAO/T-HEHS-95-67, Jan. 27, 1995).

Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994).

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